

## Book of the month

### Ethical Issues in Maternal-Fetal Medicine

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The clinicians who developed technologies for assisting human reproduction had a double motivation. Paternalistic concern to help women experiencing difficulties with reproduction was coupled with a utilitarian ethic that assumed that such innovations would result in more benefit than harm. Current techniques—donor insemination, the induction of ovulation, in-vitro fertilization, antenatal screening for fetal abnormality, antenatal diagnosis (with the option of abortion), and fetal treatment in utero—were accepted because of their obvious benefits. They became routine practice long before adverse effects were quantified, and before it became apparent that the clinicians' assumptions of the benefits to women and their children had been simplistic: in-vitro fertilization has resulted in the birth of children disabled by the prematurity associated with multiple pregnancy; after normal conception, the notion of pregnancy as a natural and rewarding process has been undermined by pressures to accept antenatal diagnosis and fetal monitoring.

Discussion of ethical issues and legal regulation has followed rather than led the developments in maternal-fetal medicine. The autonomy of the woman and the moral status of the fetus are central to the debate. Western secular ethics gives priority to personal autonomy, but in matters of sex and reproduction society persists in assigning more autonomy to men than to women. Men often coerce their partners into undesired sexual activity. Unintended pregnancy is disproportionately harmful to women yet their default behaviour is expected to be acceptance both of the pregnancy and of the obligation to care for the child. Full autonomy for women means equality in sexual behaviour and complete personal authority over the fetus.

But what is the moral status of the fetus? It is not 'new life'—the intracellular biological processes of the fetus are in direct continuity with those of the women, with the man adding only his half of the chromosomal genes. The fetus acquires moral status progressively throughout pregnancy, a progress that is marked by developmental milestones such as formation of the neural tube, completion of macroscopic organogenesis, functional maturation of lungs, liver and kidneys, increasing electrical maturation of the cerebral cortex, and then birth itself. Increasing moral status is also marked by the bonding that results from the woman's growing awareness of the fetus, and which, as the pregnancy becomes increasingly obvious, extends to her partner, her family, and then everyone she meets. This

bonding with the fetus is the foundation for the responsibility she feels for the welfare of the future child. Birth itself is a major moral event. By 'giving birth', the woman confers to her new baby status as a person. The baby, unlike the fetus, does not have an obligatory dependence on the woman, and adaptation to extra-uterine life has necessitated sudden, radical and irreversible changes in its circulation and respiration. British law supports the view that the fetus is not a person at any gestation, and recent case law has established that the consent of the woman is required for any intervention in pregnancy that is considered necessary to benefit or to reduce the risk of harm to the fetus. After birth, the baby is legally a person who, if not provided with adequate care, has special protection under the Children Act. In contrast to the fetus, the wellbeing of the child is the responsibility of both parents and of society as a whole.

There are practical difficulties in respecting the autonomy of the pregnant woman when providing the potential benefits of maternal-fetal medicine. The woman's view of pregnancy as a rewarding natural process differs from that of the health professionals who are primarily motivated to minimize the risks to her and her fetus. The offer of screening and antenatal diagnosis of fetal abnormality disturbs the woman's positive view of her pregnancy, but she may have difficulty in refusing what appears to her to be a routine part of antenatal care—something she does not fully understand, and that she cannot easily discuss in the crowded minutes she spends with the professionals in the antenatal clinic. She tends to accept the tests on offer and only later becomes truly aware of their positive and negative value for her. Techniques such as ultrasound imaging and fetal heart rate monitoring bond the clinicians to the fetus and create the illusion that the fetus is a person, a patient, for whom they are directly responsible. The clinicians' relationship with the woman can deteriorate and become adversarial when their view of what is good for the fetus differs from hers. Such disagreement has two causes: the first is correctable by effective education and results from lack of accurate knowledge and understanding by the woman; the second has to be accepted and is a consequence of deeply conditioned cultural differences between the woman and the healthcare providers. This may result in an adverse outcome that was potentially avoidable; but experienced obstetricians know that adverse prognoses are sometimes disproved—and that a woman who initially rejects necessary interventions will often accept the recommended management once time has passed and it has become clear that disaster looms. Ethical care should aim at ensuring that the woman remains responsible for herself and her fetus and that she retains her trust in the health professionals providing her care: it is not right to attempt to use the

courts to force a competent woman to have treatment against her will.

Innovations in maternal–fetal medicine must not only respect the autonomy of the woman but must also be beneficial and unlikely to cause serious harm. The balance between benefit and harm can be estimated prospectively but, very importantly, can also be measured retrospectively by the methods of audit that are part of evidence-based medicine. The provision of audit should be a requirement before any new method is introduced experimentally: it is not enough to design follow-up studies after a method has passed into general use and unforeseen harm has been done.

Justice is a neglected principle in maternal–fetal medicine—as it is in the application of new techniques and drugs in medicine as a whole. This is particularly true for infertility techniques that are expensive and difficult to provide through the National Health Service. The lack of NHS services has led to the growth of independent providers whose rates are determined by the market. The regulation of the independent sector by the Human Fertilisation and Embryology Authority—inspection, registration and the monitoring of outcomes—is much more important than its duty to impose ethical limits for the use of gametes and embryos, formulated more than 10 years ago during heated debates in Parliament. These should be the responsibility of a non-political national ethical committee that could vet and authorize innovative research and, when the balance of outcomes is clearly beneficial, approve routine use.

The above paragraphs express my personal view after reading *Ethical Issues in Maternal–Fetal Medicine*<sup>1</sup>. The book itself is not so prescriptive and has a much wider scope. The editor, Donna Dickenson, has written a skilful overview that brings together chapters by individual authors from Britain (11), North America (8), and Scandinavia (2). The treatment of an issue often reflects the nationalities and the professional backgrounds of the writers—which include moral philosophy, political science, law, and clinical

practice. The aim is to stimulate thought rather than to guide treatment in detail. The authors vary in their perspectives and often question established views: for example, reproductive cloning is not necessarily an insult to human dignity; there may be advantages in recruiting semen donors from mature men who are willing for their identity to be known by the resulting children; a woman should have some property rights in fetal or placental tissue when these result in commercially successful therapies; commercial surrogate pregnancy is rejected because the surrogate and her immediate family inevitably bond to the child that will be born; arguments are presented against the views of some politically active disabled people that negative attitudes towards them are encouraged by abortions for fetal abnormality. There is a well considered chapter by Carson Strong on the moral status of the fetus. The chapters by practising clinicians are particularly helpful to those who currently provide services for pregnant women: Paquita de Zulueta deals with HIV in pregnancy; Susan Bewley discusses the problems posed by women who reject medical advice in pregnancy; Wendy Savage analyses whether women should have the option of vaginal delivery or caesarean section; Neil McIntosh presents ethical issues in withdrawing life-sustaining treatment from handicapped neonates. An omission is any debate on the paradox that helping women to conceive desperately wanted children is seen by an influential minority of our society to need statutory regulation, whereas fertile couples have freedom to conceive just as they wish. This is not a textbook but a valuable contribution to a continuing discussion.

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#### REFERENCE

- 1 Dickenson DL, ed. *Ethical Issues in Maternal–Fetal Medicine*. Cambridge: Cambridge University Press, 2002 [353 pp; ISBN 0-521-664-748; £24.95 p/b].

## Communicating with Dying Patients and their Relatives

Jean Lugton

184 pp Price: £19.95 ISBN 1-85775-584-7

Abingdon: Radcliffe Medical Press, 2002

Jean Lugton is a nurse with long experience of research and training in palliative care. As such she has excellent understanding of the stresses and pressures that professionals feel when faced with dying patients and their relatives. It is appropriate therefore that, after a brief chapter defining terminal illness, she talks about the needs of staff caring for terminally ill people. Not many authors would have the courage to focus on our personal needs as professionals before addressing the practicalities of communication.

The need to reflect on our personal concerns, approaches and abilities is brought out further by the questions and exercises at the end of each chapter. These are often of the nature of 'How can this be achieved in your clinical area?'. In the final chapter Lugton brings out the fact that patients may need different levels of communication and support and relates this to different levels of competence in palliative nursing, with further encouragement to reflect on personal capabilities.

This personal approach throughout implies a concern for the nurses for whom she is writing and a desire to encourage readers to provide their best in their own individual situation in the difficult area of palliative care. This is not a book of high-blown theory or of distant guidelines. Lugton provides a practical book made up of different insights and illustrated by many examples from the real world as she takes us through the breaking of bad news, assessment of needs, planning of support and preparation of relatives for bereavement.

All of us who have worked in this sphere will have benefited as much from the support of a peer (of whatever profession) as from knowing what we should do. The approach of this little book should encourage us to be more active in providing this support to each other. Here are questions that we should be looking at together as healthcare teams, especially when we lack the full support of a palliative care group or a hospice.

That is how the book came over to me, but at the same time I was often worried by the structure. The foreword tells us that research and theory have been woven together but the link between theory and practical advice is sometimes hard to find. Chapter headings do not always relate well to content. In the chapter on 'Breaking Bad News' the first three-quarters is given over to considering reactions and support after the news has been given rather than the actual process. Whilst the breaking of bad news is

normally a medical responsibility, there is little input on how the different members of the team (including the nurses) might be involved: nurses often have to pick up the pieces after a bad experience, but this is addressed only by advice that 'if one member of staff is continually untactful when breaking bad news to patients, it is a clinical governance issue.' The area of spiritual care is limited to four pages; although this is seen as a communication problem, no real guidance is offered on how to open up the issue and see if help is needed. At times one feels that the author's desire to mention principles and theory is battling against the desire to make the book practical and helpful to the reader.

Although this book is intended for nurses, it would help all professions in the team to support one another. It offers many helpful insights—but look elsewhere for a clear exploration of the underlying theory.

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## Synaptic Self: How Our Brains Become Who We Are

Joseph LeDoux

406 pp Price £20 ISBN 0-333-781872 (h/b)

London: Macmillan

DH Wilkinson once calculated, rather whimsically, that an average human life lasts about  $10^9$  seconds whereas an average sensory trace lasts less than one second (pace Buddha, St John of the Cross and an extremely select group of others). Confined though I am within my own solipsistic nutshell, I know I am more than the sum of a billion-odd parts, and suspect that the same might be true of my fellow humans as well. But between sensation and experience yawns a dreadful gap, long lamented by philosophers, and latterly by neuroscientists too. Joseph LeDoux has made yet another attempt to span this chasm (here scaled to the dimensions of the synaptic cleft) in *Synaptic Self: How Our Brains Become Who We Are*. His book is a well-written and commendably comprehensive survey of many of the big ideas in modern neuroscience. It is manifestly not an answer to the question posed by its title.

LeDoux's central concern is nothing less than the synaptic interface between the ancient emotional circuitry of the limbic brain and the neocortical apparatus of cognition and motivation. The operation of this interface in emotional and goal directed behaviours and the mechanisms by which it is changed by experience are the great themes of his book. His expositions have an easy charm that belies their author's eminence. As one of the pioneers of

emotional cognition, LeDoux is entitled to his dauntless vision of the brain as the canvas of our evolutionary and personal past. He has stripped away the filmy varnish of our sentience to reveal the ancient triptych of cognition, emotion and motivation. Neuroanatomy, cellular neurophysiology, neurotransmitter pharmacology, systems physiology, behavioural psychology, functional brain imaging, clinical neurology and psychiatry are all duly painted in. There is a ghost, though, at this glorious banquet of the brain: the inner life, the 'something-it-is-like-to-be-me'-ness that has leapt, raucous and uninvited, out of the dense synaptic thicket in our heads.

LeDoux maintains that 'consciousness' is an overvalued idea in modern neuroscience, and it is difficult to argue with this. And yet, when all's said and done, our intricate inner lives are very probably unique, quite different in kind as well as in degree from those enjoyed by the many animal species that populate LeDoux's book. The subjective quality of sensory traffic, those notorious 'qualia' that have exercised philosophers from Plato to David Chalmers, may yet turn out to be fundamental to the operation of brains, rather than inconvenient epiphenomena. We know what it is to be human: we cannot imagine what it is like to be a bat, or even whether it is like 'something' at all. LeDoux's sweeping definition of the self ('the totality of the living organism') acknowledges our common mammalian heritage even as it sidesteps the problem of conscious awareness; but will this really do? In his final chapter, LeDoux rightly rejects the notion of a coordinating homunculus, crouched somewhere inside the skull, in favour of a set of seven organizational principles that confer plasticity on parallel synaptic networks and permit the brain to reinvent itself as it learns. And yet, his principles leave oddly untouched the central paradox of our experience of the grainy and chaotic world—its seamless perceptual unity in time and space.

It may indeed turn out that a sense of extension in time is fundamental to the idea of self, at least as far as human brains go; it is not at all clear that animals possess such a sense, for it anticipates a future no less than it reanimates a past. It is evidently not dependent on any single memory

mechanism, as we now understand them. For the present, it remains a true mystery; and to his credit LeDoux refuses to explain it away by resorting to neurophysiological legerdemain. The problem is, this mystery lies at the very core of human selfhood; it is the biological *sine qua non* upon which the existential angst of Sartre and friends is built. Our own existence cannot fill us with nausea, ecstasy, or perverse and peculiarly human mixtures of both, unless we first apprehend that we exist. The neural machinery that LeDoux describes would be blind and mute if something about the human brain did not insist on this ontogenetic Catch-22. The problem is no less acute in the case of our perceived spatial integrity. For LeDoux, the paradigm of a self divided is the schizophrenic patient, or perhaps the callosotomy patient with inter-manual conflict; but the clinical neurologist might point to wards filled with stroke patients who refuse even to own their left arms.

To paraphrase JBS Haldane, the brain is surely queerer than we imagine, though I trust not queerer than we can imagine. Turn to any page of Wilder Penfield's neurosurgical ancient history and you will quickly acquaint yourself with the appalling strangeness of an organ that has stored a faithful record of all the banalities it has ever suffered, alongside all its transports of delight. LeDoux's magnificently intelligible joining of parts is most seductive; but I am still bothered by niggling doubts.

All the same, his book has a refreshing humility. He acknowledges at the outset that his is not the whole story. Like the Danaids of Greek myth, neuroscientists may never finish this particular job with the tools they now have at their disposal: the leaking vessels of our present paradigms cannot contain the self in its brain. Getting inside our own qualia is proving much more difficult than getting inside the atom, but that is no reason to abandon the attempt—or worse still, to convince ourselves that we have already succeeded. *Non intellego, ergo sum.*

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